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ABSTRACT

This report examines respite care services that provide temporary relief to family members and other caretakers of children at risk of abuse or neglect including children who are mentally retarded, behaviorally disturbed, physically disabled, or chronically or terminally ill. In 1988 the 25 states surveyed funded 111 respite care programs as did six national organizations. The federal government's principal effort was awards amounting to $9.7 million for demonstration grants. Report sections focus on: respite care aims (to relieve stress, prevent child abuse, and promote family unity); federal, state, and private levels involved in respite care; state funded programs; national service organizations; federal involvement; family responses to respite care services; and suggestions for improving services (increase information and publicity, train more providers, maintain flexible programs, and enhance federal role). Nine appendixes provide detailed information on: objectives, scope, and methodology; characteristics of 111 state-funded programs by state; summary information about state-funded programs; provider eligibility and licensing requirements; results of questionnaire administered to officials of state-funded respite care programs; local chapters of national organizations with respite care programs; federal respite care grants awarded by state; comments from the Department of Health and Human Services; and major contributors to the report. Includes 109 references. (DB)

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Report to Congressional Requesters

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September 1990

RESPITE CARE

An Overview of Federal, Selected State, and Private Programs

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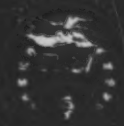

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United States
General Accounting Office
Washington, D.C. 20548

Human Resources Division

B-239731

September 6, 1990

The Honorable George Miller
Chairman, Select Committee
on Children, Youth and Families
House of Representatives

The Honorable Major R. Owens
Chairman, Subcommittee on
Select Education
Committee on Education and Labor
House of Representatives

As you requested in your August 25, 1988 letter, we reviewed the availability and use of respite care services. You asked that we (1) provide information on the characteristics, nature, and availability of respite care services; (2) obtain respite care users' views about the services provided; and (3) provide suggestions for improving respite care services and enhancing the federal role.

On April 6, 1989, we testified on the preliminary results of our review before the House Subcommittee on Select Education.[1] We stated that various definitions of respite care were in use and that little research had been directed at measuring the effects of respite care services, such as its impact on reducing child abuse and neglect. To improve the evaluation of respite care programs, we suggested that programs should begin collecting data on services provided, families served, and costs. On October 25, 1989, pertinent legislation, the Children With Disabilities Temporary Care Reauthorization Act of 1989 (P.L. 101-127), was enacted. It reauthorized federal respite care demonstration grants and required that programs begin gathering more specific data as a step toward evaluating the effects of respite care programs. In commenting on a draft of this report, HHS indicated that by 1992 its evaluation of respite care services would be enhanced as a result of this legislation and other data it is collecting.

This report provides the final results of our review. As agreed with your offices, we focused on respite care services that provide temporary relief to family members and other caretakers of children who may be at risk of abuse or neglect. This includes children who are mentally retarded, behaviorally disturbed, physically disabled, or chronically or

[1] Respite Care Insights on Federal, State, and Private Sector Involvement (GAO/T-HRD-89-12, Apr. 6, 1989).

terminally ill. Nearly 2.2 million children were reported as victims of abuse or neglect in 1988, according to a 1989 study by the House Select Committee on Children, Youth and Families. Also, as reported in a 1989 Department of Education report to the Congress, about 1.1 million children were classified as mentally retarded by school special education units in school year 1987-88. To obtain the information you requested, we sent questionnaires to program officials in 25 states; conducted group interviews with state program officials, service providers, and parents; and interviewed federal and state government and national organization officials responsible for respite care programs and other experts. Our work was conducted between February 1989 and February 1990. Additional details on the scope and methodology of our review are provided in appendix I.

Results in Brief

Respite care is a relatively new and evolving social service. Programs offering respite care services are administered and funded by state agencies, national organizations, and federal departments and agencies. Because information on respite care is limited, we were unable to account for all programs and funding provided for it. However, this report presents the information that we were able to obtain on respite care services.

In fiscal year 1988, the 25 states we surveyed funded 111 respite care programs. We also identified six national organizations, including the Easter Seal Society and United Cerebral Palsy Association, that provide respite care services through 279 of their local chapters in 221 cities of 44 states and the District of Columbia. Although several federal departments and agencies are involved in respite care, the federal government's principal effort consists of awards by the Department of Health and Human Services (HHS), amounting to about $9.7 million for demonstration grants in fiscal years 1988 and 1989.

While little evidence is available on the efficacy of respite care, users have found the services beneficial in giving them more time to attend to other family and daily-living activities. State program officials, service providers, and parents who participated in our group discussions believe that the demand for respite care exceeds the supply available. They suggested improving respite care services by increasing the amount of information and publicity about available programs, training more providers, and allowing programs to be tailored to individual families' specific needs. State officials and providers also offered several suggestions concerning the federal government's role in respite care. One

was to offer incentives, such as demonstration and matching grants, to the states to focus greater attention on respite care.

Respite Care Aims to Relieve Stress, Prevent Child Abuse, and Promote Family Unity

Respite care provides temporary child care relief to family members and other caretakers of children who may be at risk of abuse or neglect. These include children who are mentally retarded, behaviorally disturbed, physically disabled, or chronically or terminally ill. Respite care also may be targeted to foster parents and unemployed parents. The purpose of respite care is to relieve stress temporarily and thus prevent child abuse and neglect and support family unity. Undue stress within a family, whether caused by the burdens of caring for a disabled child or such factors as financial worries, is strongly linked with child abuse. Abuse, neglect, or a family's inability to cope with the disabled child may lead to the child's placement in an institution or foster care. Respite care seeks to support the family as a whole by providing a break for parents and a safe place for the child for a short period of time.

Respite care has several characteristics. It is temporary and is directed at the parent or other caretaker—though the child's needs also may require a specially trained respite care provider. Respite care can be planned and act as a preventive service before a crisis is reached. It also can be an emergency service, such as a crisis nursery that specializes in providing short-term crisis care to abused and neglected children.

As a recognized social service, respite care is relatively new. Like many social services, it originated at the grassroots level. The need for family support services such as respite care became apparent in the early 1970s. It followed the movement to allow disabled persons, particularly children, to remain with their families instead of being placed in an institution. Crisis nurseries began at about the same time.

Federal, State, and Private Levels Involved in Respite Care

State and local agencies, national organizations, and federal departments and agencies fund respite care services. In the 25 states surveyed, the administration of respite care services entailed an intricate web of intergovernmental and private entities, whose patterns of funding and operation differed from state to state. Services and operations also varied considerably among the different providers.

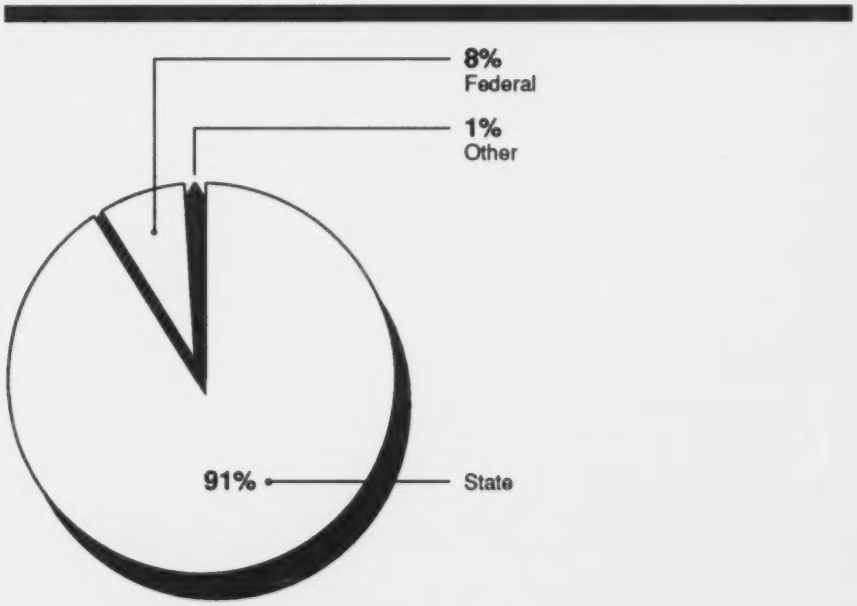
Because program and funding information was not always available, we were unable to develop a complete account of all programs and funds provided for respite care within the 25 states surveyed. Also, some

states provided funds to chapters of national associations for respite care activities. Thus, the information presented below for the states, national organizations, and federal departments and agencies may in some instances double-count the programs and funds provided for respite care.

Surveyed States Funded 111 Respite Care Programs

Respite care programs in the 25 states surveyed varied greatly in size and funding levels. In fiscal year 1988, state agencies in these states funded 111 respite care programs that provided services locally. Expenditure data were available for only 62; for these programs, states provided about 91 percent of the $84 million funding in fiscal year 1988 (see fig. 1). Individual program expenditures ranged from $3,000 to $15 million. Appendix II provides additional details about the 111 programs by state.

Figure 1: Funding Sources for 62 State-Funded Respite Care Programs (FY 1988)



The 111 state-funded programs offered a variety of respite care services, including temporary child care; personal care, such as bathing, dressing, and grooming; and companionship services. Along with these

services, non-respite-care support services were provided, including family counseling, training for disabled children to function independently, and occupational/physical therapy.

While eligibility criteria vary among the 111 state-funded programs, the child's condition and age were overriding considerations in determining a family's eligibility for respite care services. Generally eligible were families with children who were developmentally disabled, mentally retarded, chronically or terminally ill, and behaviorally or emotionally disturbed. Almost all programs allowed families to receive respite care services from the time a child was born to age 22. Some programs had no upper age limits for eligibility. Income generally was not an eligibility determinant; most programs provided services at no cost to the family. For the few state-funded programs that required payment for services, most fees were on a sliding scale, based on the families' ability to pay.

Respite care services provided by the state-funded programs were offered in the parents' or caretakers' home and other locations outside the home. Out-of-home services usually were furnished in relatives' homes, licensed foster homes in which foster parents provided temporary respite care services, or respite care group homes, in which both client and community provider lived while respite care services were provided.

Additional summary information about the 111 state-funded respite care programs, such as the types of services provided, fee structures and provider eligibility or licensing requirements, are included in appendixes III through V.

National Service Organizations Are Major Providers

Many respite care programs are administered by national organizations—private, nonprofit service associations and societies—that began providing such services in the 1970s. We identified six national organizations (see table 1) that provide respite care services through 279 local chapters located in 221 cities of 44 states and the District of Columbia. The national organizations did not have detailed information on the funds spent and number of families served by their local chapters. Appendix VI identifies the states in which these organizations provide respite care services.

Table 1: National Organizations Providing Respite Care Services in 44 States and the District of Columbia

Organization	Local chapters providing respite care	States covered
Camp Fire	90	35
Easter Seal Society	37	26
National Council on Aging	10	8
National Down Syndrome Society	5	3
United Cerebral Palsy Association	50	21
Visiting Nurses Association of America	87	29
Total	**279**	

Using different approaches, the national organizations variously provide respite care services in the child's home, outside the home, and through educational services. For example:

- The National Down Syndrome Society brings together Down Syndrome children and host families who volunteer to care for the children one weekend every 6 weeks over a 1-year period. The program also seeks to foster independence in the children and educates host families and communities about Down Syndrome.
- The National Council on Aging's Family Friend Program matches older volunteers with chronically ill and disabled children. Once a week, the volunteers visit these children in their homes and provide psychological and social support to the children, parents, and other family members.

Federal Involvement Limited

The federal government's involvement in respite care has been limited mostly to demonstration programs funded by HHS. Under the Temporary Child Care for Handicapped Children and Crisis Nurseries Act of 1986, the Congress directed that HHS establish a demonstration program of grants to states. These grants are to help provide (1) temporary, nonmedical child care to families having children with disabilities or with chronic or terminal illnesses and (2) crisis nurseries for children who are abused and neglected, at high risk of abuse and neglect, or in families receiving child protective services.

In fiscal years 1988 and 1989, HHS awarded about $9.7 million to 42 states and Puerto Rico for 67 demonstration grants. About $4.7 million was awarded for 32 temporary handicapped child care grants and $5 million for 35 crisis nursery grants.

An example of a project funded by HHS is a $150,000 demonstration grant to the Missouri Department of Mental Health. It finances the training of providers to perform in-home and out-of-home respite care services for 50 children. Missouri's Department of Mental Health expects to provide services to families with children who have multiple disabilities. These are families who most need relief from the stresses of giving primary care and are thought to have the smallest pool of providers from which to choose.

Another project is a $150,000 demonstration grant to the Texas Department of Health to develop a state plan for providing respite care services for infants with special needs. The project's goals include implementing model respite care projects in rural Texas and coordinating state resources to improve accessibility to respite care services.

Recent legislation authorized additional funds to HHS for respite care demonstration projects. In October 1989, the Children With Disabilities Temporary Care Reauthorization Act authorized $20 million for fiscal year 1990 and an additional $20 million for fiscal year 1991 for temporary child care and crisis nursery grants. The legislation stipulates that reports be submitted on project costs, family stability, incidence of abuse or neglect, services provided, and recipients' demographic data. About $8.3 million in grants are expected to be awarded in fiscal year 1990 to fund up to 20 new demonstration projects and to extend some of the 67 previously funded projects.

Other HHS programs have provided funds for respite care, such as Medicaid's financing of home and community-based services for disabled individuals. However, we were unable to obtain information on the amount of funds provided.

In addition to HHS, we identified several other federal departments and agencies that provide limited respite care services:

- ACTION, an independent federal agency that administers volunteer service programs, provides respite care services through its Foster Grandparent Program. Through 328 local programs, ACTION employs low-income elderly people to act as foster grandparents to special-needs children. The agency also has provided a $25,000 grant to the National Down Syndrome Society to help communities across the nation replicate the society's respite care program, as indicated on page 6.
- In the Department of Defense, the Department of the Army has the most extensive formal program. The Army provides respite care services to

its personnel through 232 programs located on and outside its installations and 107 foster care programs in the United States and overseas. Although the Department of the Navy has no formal respite care program, Navy officials said that it has programs at six locations worldwide that together spend about $62,000 annually on respite care-related activities. The Air Force and Marine Corps also have no formal programs, but officials said that volunteers, community resources, and nonappropriated funds are used to support respite care functions. These services also use child development centers for respite care on an infrequent basis.

- The Department of Education has funded three grants, each for $30,000, to (1) perform a national survey of families on their knowledge of respite care, (2) develop materials for families on how to use and identify sources of funds for respite care services, or (3) develop informational products to enhance the supply and use of respite care services. In addition, the Department of the Interior has a project that involves a homemaker providing respite care services to families on an Indian reservation in Mississippi.

No information was available on the amount of respite care funding or the number of families served for several of these federal programs. Appendix VII identifies the states in which federal grants for respite care have been awarded since 1983.

Families Find Respite Care Services Beneficial, but Limited

Parents participating in our group discussions about respite care said that such services help reduce the stress associated with caring for their disabled children and permit them to perform other routine daily family activities. For example, respite care services give family members and other caretakers time to shop for groceries, get to doctor appointments, and meet the normal needs of other siblings. Respite care also gives parents time to spend with each other or attend special events, such as family weddings and graduation ceremonies. Some families said that they rely on respite care providers to care for older disabled children whose size, weight, and physical development make them more difficult to care for than younger children.

State program officials, local providers, and respite care users expressed views that the demand for respite care services exceeds the supply available. As noted in our testimony, little information is available on the numbers of families being served or needing respite care services. Thus, we were unable to measure the demand for such services. However, information provided by state program officials provides some

indications that the demand for respite care services exceeds the available supply. For example, 40 state-funded programs had identified about 3,700 families on waiting lists maintained during fiscal year 1988. (Sixty-nine programs did not maintain waiting lists, and two did not indicate that they had such lists.) In addition, 77 programs had referred families to other social programs for respite care services because the families had requested more services than were available or the number of families and other caretakers requesting services exceeded those available. (The remaining 34 programs either did not refer families or did not indicate if they made referrals.)

Respite Care Users, Providers, and State Officials Offer Suggestions

Participants in our group discussions made several suggestions for improving respite care services, including increasing the information and publicity about available services, training more providers, and maintaining flexible programs. They also believe that the federal government's role could be enhanced by offering states incentives, such as demonstration and matching grants, to focus greater attention on respite care.

Increase Information and Publicity About Available Services

Respite care users believe and state officials agree that more information about the availability of respite care services is needed. Family members participating in our group discussions said that information about and referrals for respite care services are scarce and difficult to obtain. Program officials in one state indicated that no central entry point for respite care services is available and that departments within the state are unaware of each other's respite care activities.

We identified two state networks—the Texas Respite Resource Network and the Nebraska Resource Referral System—that make respite care information available to families as well as to local agencies. The Texas network is an information clearinghouse and also provides technical assistance to parents, agencies, and programs throughout the United States. Nebraska has a state computerized system of information and referral services with emphasis on children with special needs.

Train More Providers

A need for specialized training of respite care providers was expressed by parents using respite care services, especially parents of disabled children. They had difficulty finding respite care providers trained to care for children who have severe emotional problems, are medically fragile, or are dependent on technical medical equipment. The parents

suggested that the states be responsible for recruiting and training providers for children with these disabilities. Local providers of respite care also commented on the need for more trained providers to deal with the special needs of disabled children.

Maintain Flexible Programs

Participants in our group discussions said that respite care services need to be tailored to individual families. Families should be able to select the provider and determine the level of care and kinds of services needed, participants asserted. For example, a Michigan program offers cash subsidies to families that permit them to find their own provider and determine their own level of services. A Connecticut state program official said that families should be given funds and permitted to purchase their own services.

Enhance Federal Role

State respite care officials and local providers offered several suggestions for the federal government's role in respite care. Several said that the federal government should offer states incentives, such as demonstration or matching grants or some type of reimbursable financial arrangements, to focus greater attention on respite care. Some believed, however, that to have the most positive effects on families, such incentives should encompass more than respite care. A focus on the whole spectrum of family support services, such as day care and recreational services, was suggested. State officials suggested that if more federal money is made available, it be used for such activities as outreach efforts or recruiting and training providers to care for children with special medical needs or emotional disorders. A state official and several local providers expressed concern that the federal government not regulate or establish standards for respite care.

Agency Comments

HHS agreed with the information we gathered on respite care services and with the suggestions made by respite users, providers, and state officials for improving respite care services. It believed, however, that additional data on such services were needed before public policy is formulated.

As arranged with your office, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days from the date of this letter. At that time, we will send copies to the Secretary

of Health and Human Services, the Director of the Office of Management and Budget, and other interested parties.

Please contact Mr. Gregory J. McDonald on (202) 275-5365, if you or your staff have any questions concerning this report. Other major contributors to this report are listed in appendix IX.

Lawrence H. Thompson

Lawrence H. Thompson
Assistant Comptroller General

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Abbreviations

GAO	U.S. General Accounting Office
HHS	Department of Health and Human Services

Objectives, Scope, and Methodology

Objectives

The Chairman of the House Select Committee on Children, Youth, and Families and the Chairman of the House Subcommittee on Select Education of the Committee on Education and Labor asked us to review the availability and use of respite care services. As agreed with the Chairmen's offices, we obtained information on the following:

- The availability and nature of respite care programs in the United States and characteristics of families eligible to receive such services;
- How families use respite care services, what difference these services make in their lives, and how families cope without such services; and
- Views of program officials, service providers, and users on enhancing the federal government's role in respite care and how existing services could be improved.

Scope and Methodology

To obtain the requested information, we (1) sent a questionnaire to state respite care program officials in 25 states; (2) conducted group discussions with selected state officials, local providers, and family members; (3) interviewed officials of and obtained data from federal departments and agencies and national, private, nonprofit service associations and societies; and (4) reviewed the literature on respite care. Our work was performed from February 1989 through February 1990.

The 25 states to which we sent a questionnaire to learn more about state respite care programs were selected on the basis of the number of handicapped children that states reported during school year 1987-88 (see app. II.). These states account for about 80 percent of such children. Some of the states also had high rates of child abuse in calendar year 1986. Through our questionnaire (see app. V), we obtained the following information about respite care activities in the 25 states surveyed: (1) background data on the states' respite care program, (2) types of respite care services and delivery settings, (3) eligibility criteria for receiving services, (4) client costs for services, (5) provider eligibility or licensing requirements and monitoring, (6) funding sources, and (7) characteristics of people served. We did not independently verify the data provided.

We conducted five group interviews: one with state respite care program officials, two with local respite care providers, and two with Detroit family members. The latter had used respite care services or were on waiting lists for them. During the sessions, we asked for the groups' views on a number of respite care issues. State officials were queried as to their ability to meet respite care needs in their state and the need for

a federal role in respite care. Local providers discussed the availability and use of respite care services, families' satisfaction with respite care services, the impact of respite care on families and other caretakers, and the federal role in respite care. Family members focused on their need for respite care services, the availability of such services, and their satisfaction with respite care services.

To identify respite care activities, we interviewed officials of and obtained information from selected federal departments and agencies and national organizations. The federal departments and agencies included in our review were the Departments of Defense, Education, HHS, and the Interior, and ACTION. We also contacted 21 national organizations that were primarily associated with health and handicapped activities to determine their involvement in respite care. Six of these national organizations identified local chapters or affiliates that have respite care activities (see app. VI).

In addition, we conducted extensive literature searches to identify data on respite care activities and its impact on reducing stress and abating child abuse and neglect. We also asked state questionnaire respondents to identify and furnish us any studies on respite care effectiveness. Finally, we interviewed respite care experts to obtain their insights on respite care.

Characteristics of 111 State-Funded Respite Care Programs, by State (1988)

State/type of administering agency	Year begun	Statewide services	Target group coverage	Total funding	Families served	Services	
						In-home	Out-of-home
Alabama							
Human resources	1935	Yes	a,h	c	c	Yes	Yes
Mental health/ mental retardation	1988	No	d	c	c	No	Yes
	1985	No	Broad[e]	$21,760	c	Yes	Yes
Rehabilitation and crippled children	1976	Yes	f,g	1,750,000	550	Yes	No
Arkansas							
Developmental disabilities	1988	Yes	Broad	c	c	Yes	Yes
	1980	No	Broad	c	c	Yes	Yes
	1979	Yes	Broad	c	c	No	Yes
Human services	1983	Yes	a	c	c	Yes	No
California							
Developmental services	1978	Yes	Broad	15,211,876	c	Yes	Yes
Education	1984	Yes	h	1,719,000	c	No	Yes
Health services	1985	No	Broad	260,711	c	No	Yes
Colorado							
Developmental disabilities	1984	Yes	Broad	c	c	Yes	Yes
	1981	No	Broad	85,743	c	Yes	Yes
Social services	1988	No	f,h	590,000	19	Yes	Yes
	1980	No	Broad	104,000	c	No	Yes
Connecticut							
Child protection	1979	No	h	29,085	c	Yes	Yes
Children and youth	1986	No	a	109,634	24	No	Yes
	1986	No	a,b	c	c	No	Yes
Education support	1974	No	Broad	41,789	c	No	Yes
Family support	1986	No	a,h	39,240	210	No	Yes
Health services	1982	Yes	Broad	596,750	443	Yes	Yes
	1980	Yes	Broad	c	c	Yes	Yes
Mental retardation	1988	Yes	h,i	c	c	Yes	Yes
	1983	Yes	Broad	c	979	Yes	Yes
	1960	Yes	h,i	c	200	No	Yes
Florida							
Developmental services	1973	Yes	Broad	c	c	Yes	Yes
Health and rehabilitation	1988	No	Broad	57,709	35	Yes	Yes
	1987	No	Broad	c	c	No	Yes
	1983	No	a	318,692	203	No	Yes
Medicaid	1982	Yes	Broad	8,514	c	Yes	Yes

(continued)

State/type of administering agency	Year begun	Statewide services	Target group coverage	Total funding	Families served	Services	
						In-home	Out-of-home
Illinois							
Child/family services	1987	Yes	[a,b]	[c]	[c]	Yes	Yes
	1964	Yes	[a]	4,491,400	[c]	Yes	Yes
Crippled children	1985	Yes	Broad	[c]	[c]	Yes	No
Mental health/ developmental disabilities	1980	No	Broad	4,205,692	3,350	Yes	Yes
Rehabilitation services	1980	Yes	Broad	145,000	177	Yes	No
	1979	Yes	[h]	[c]	[c]	Yes	No
Indiana							
Human services	1987	No	[a]	142,875	[c]	No	Yes
Mental health	1981	Yes	Broad	1,189,356	1,100	Yes	Yes
Public welfare	1980	Yes	Broad	136,697	[c]	Yes	Yes
Iowa							
Human services	1987	No	[h]	[c]	[c]	Yes	No
	1984	Yes	Broad	3,504	[c]	No	Yes
Kentucky							
Human resources	1983	Yes	Broad	604,312	565	Yes	Yes
Mental health/ mental retardation	1980	Yes	[i]	955,078	[c]	Yes	Yes
Medical services	1987	Yes	[h]	325,824	592	Yes	Yes
Social services	1988	Yes	[b]	[c]	[c]	Yes	Yes
	1988	No	Broad	[c]	[c]	Yes	No
	1985	Yes	Broad	[c]	[c]	Yes	Yes
Louisiana							
Community services	1988	Yes	[b,h]	6,063	[c]	No	Yes
	1986	No	[b]	24,300	75	Yes	Yes
	1984	No	Broad	[c]	[c]	Yes	No
	1980	Yes	Broad	1,234,724	904	Yes	Yes
Mental retardation/ developmental disabilities	1983	Yes	Broad	[c]	[c]	Yes	Yes
Massachusetts							
Mental retardation	1984	Yes	[i]	3,000,000	[c]	Yes	Yes
	1979	Yes	Broad	15,000,000	10,000	Yes	Yes
Public health	1976	Yes	[f]	122,000	288	No	Yes
	1975	Yes	[f]	426,500	205	Yes	No
Public welfare	1984	Yes	[d,i]	[c]	[c]	Yes	Yes
Michigan							
Developmental disabilities	[c]	Yes	Broad	[c]	[c]	Yes	Yes
Mental health	1985	Yes	Broad	334,569	43	Yes	Yes
	1984	Yes	Broad	[c]	[c]	Yes	Yes
	1984	Yes	Broad	[c]	3,000	Yes	Yes
Social services	1988	No	Broad	3,000	[c]	Yes	Yes

(continued)

State/type of administering agency	Year begun	Statewide services	Target group coverage	Total funding	Families served	Services	
						In-home	Out-of-home
Minnesota							
Developmental disabilities	1984	Yes	Broad	793,000	[c]	Yes	Yes
Human services	1987	No	[h]	[c]	10	Yes	Yes
	1985	Yes	[h]	9,815	[c]	Yes	Yes
	1976	Yes	Broad	[c]	[c]	Yes	Yes
Missouri							
Mental health	1985	No	[b,d]	3,000	8	Yes	Yes
Mental retardation/ developmental disabilities	1975	Yes	Broad	[c]	[c]	Yes	Yes
Social services	1984	No	[a,b]	26,801	68	Yes	Yes
New Jersey							
Health	1978	Yes	[h]	280,000	25	Yes	No
Human services	1984	Yes	[h]	470,251	[c]	Yes	No
	1983	Yes	[d]	[c]	[c]	No	Yes
Developmental disabilities	1980	Yes	[h]	3,234,843	[c]	Yes	Yes
New York							
Health	1986	No	Broad	186,619	88	Yes	No
Mental health	1982	Yes	[d,h]	330,500	177	Yes	No
Mental retardation/ developmental disabilities	1985	Yes	Broad	15,000,000	13,000	Yes	Yes
Social services	1986	Yes	[f,h]	[c]	[c]	Yes	No
North Carolina							
Mental health/ mental retardation/ substance abuse services	1988	No	[h]	60,400	18	Yes	Yes
	1975	Yes	Broad	[c]	[c]	Yes	Yes
Human resources	1983	Yes	Broad	24,394	49	Yes	Yes
	1983	No	Broad	[c]	[c]	Yes	Yes
	1981	Yes	Broad	[c]	150	Yes	Yes
Ohio							
Community services	1983	Yes	Broad	2,849,970	[c]	Yes	Yes
Human services	1986	No	[a]	3,780	19	No	Yes
	1985	No	[a]	142,365	257	No	Yes
	1983	Yes	Broad	[c]	[c]	Yes	Yes
Mental health	1988	Yes	[a,d]	[c]	[c]	Yes	Yes
Oklahoma							
Child welfare	1970	Yes	Broad	[c]	[c]	Yes	Yes
Health	1987	No	Broad	45,500	150	No	Yes
Human resources	1985	Yes	Broad	119,699	205	Yes	Yes
Mental health	1986	No	Broad	700,000	200	Yes	Yes
Social services	1985	Yes	Broad	84,000	60	No	Yes

(continued)

State/type of administering agency	Year begun	Statewide services	Target group coverage	Total funding	Families served	Services	
						In-home	Out-of-home
Pennsylvania							
Mental health	1988	No	d,h	38,167	c	Yes	Yes
	1986	Yes	d	c	c	Yes	Yes
Mental retardation	1973	Yes	i	3,626,228	6,809	Yes	Yes
Tennessee							
Mental health/ mental retardation	1978	No	Broad	71,921	140	Yes	Yes
	c	Yes	i	130,000	c	Yes	Yes
Social services	1987	No	a	c	11	No	Yes
	1985	No	a,h	10,000	16	No	Yes
Texas							
Human services	1988	No	Broad	c	4	Yes	Yes
	1985	No	i	101,292	c	Yes	Yes
	1985	Yes	f	100,712	15	Yes	No
Mental health/ mental retardation	1988	Yes	d,h,i	c	25	Yes	Yes
	1985	Yes	Broad	c	c	Yes	Yes
	1987	No	Broad	c	1,246	Yes	Yes
Virginia							
Mental health/ mental retardation/ substance abuse services	1979	No	h	c	c	Yes	Yes
	c	Yes	a,d	c	c	Yes	Yes
Washington							
Developmental disabilities	1981	Yes	Broad	c	c	Yes	Yes
Family services	1984	Yes	b	c	c	Yes	Yes
Mental health	1979	No	b,d	c	c	No	Yes
Social/health services	1974	Yes	Broad	2,031,146	c	Yes	Yes

[a]Children at risk of abuse or neglect

[b]Foster care children

[c]Data unavailable

[d]Behaviorally or emotionally disturbed children

[e]"Broad" targeting means the program covered the developmentally disabled or all or most of the following groups: mentally retarded, physically handicapped, chronically ill, visually impaired or blind, speech or hearing impaired, behaviorally or emotionally disturbed, abused or neglected, or foster care children.

[f]Medically or physically handicapped children

[g]Chronically or terminally ill children

[h]Mentally retarded children

[i]Other

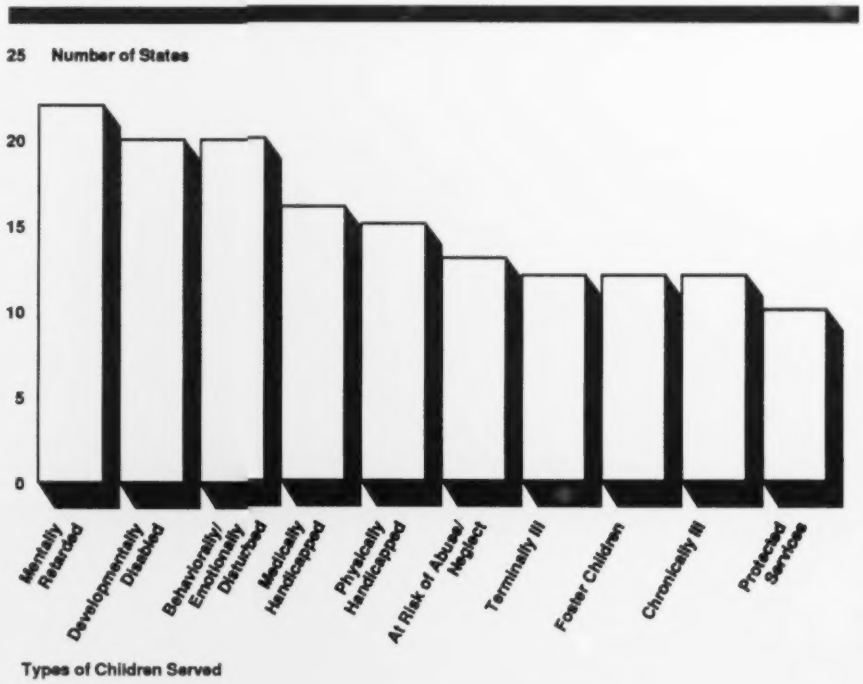
Summary Information About 111 State-Funded Respite Care Programs

Respite care program officials in the 25 states surveyed identified 111 state-funded respite care programs. Information we obtained about these programs through our survey included (1) eligibility criteria for receiving services, (2) types of services provided, (3) fee structures for services, (4) service delivery settings, (5) sources of information about available services, and (6) provider requirements and state monitoring. Following is a summary of the information.

Eligibility Criteria

In almost all state-funded programs, eligibility for respite care services was based on the age and condition of the disabled child. Families' and other caretakers' income was also an eligibility criterion for 32 programs. As illustrated in figure III.1, most of the states funded programs that offered respite care services to families with children who were mentally retarded, developmentally disabled, and behaviorally and emotionally disturbed.

Figure III.1: Types of Children Served by Respite Care Programs in 25 States Surveyed (FY 1988)

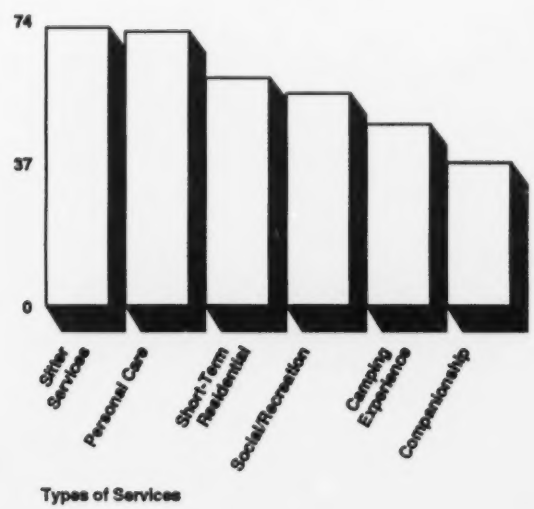


Ninety-seven programs provided respite care services from the day the child was born. Seventy-one programs discontinued services when the child reached age 22, while 29 programs provided respite care throughout the child's life.

Types of Respite Care Services

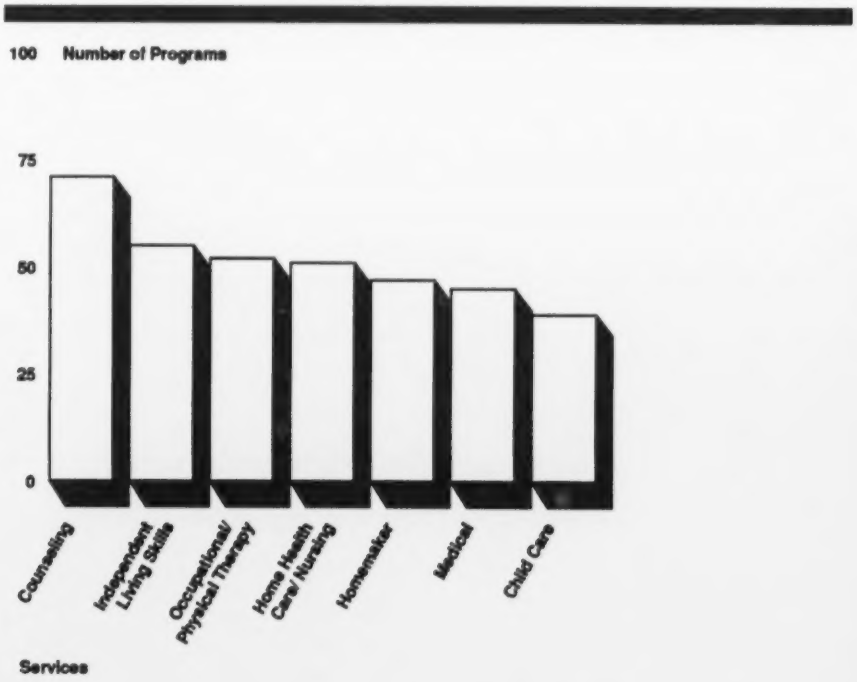
A variety of respite care services were provided by the 111 state-funded programs in fiscal year 1988, as shown in figure III.2. For example, 71 programs provided respite care services in the form of personal care services that included bathing, dressing, and grooming; meal preparation and feeding; light housekeeping and laundering; shopping; and transportation. Also, 59 programs provided respite care services in a residential facility designed to provide such services for short intervals.

Figure III.2: Types of Services Provided by 111 State-Funded Respite Care Programs (FY 1988)



In addition to respite care, 100 state-funded programs provided other support services (see fig. III.3). These include independent living skills that helped the children prepare to live on their own; occupational and physical therapy administered for major limbs and muscles; home health care, including nursing and therapy; and child care that provided temporary arrangements for the children while the parents worked.

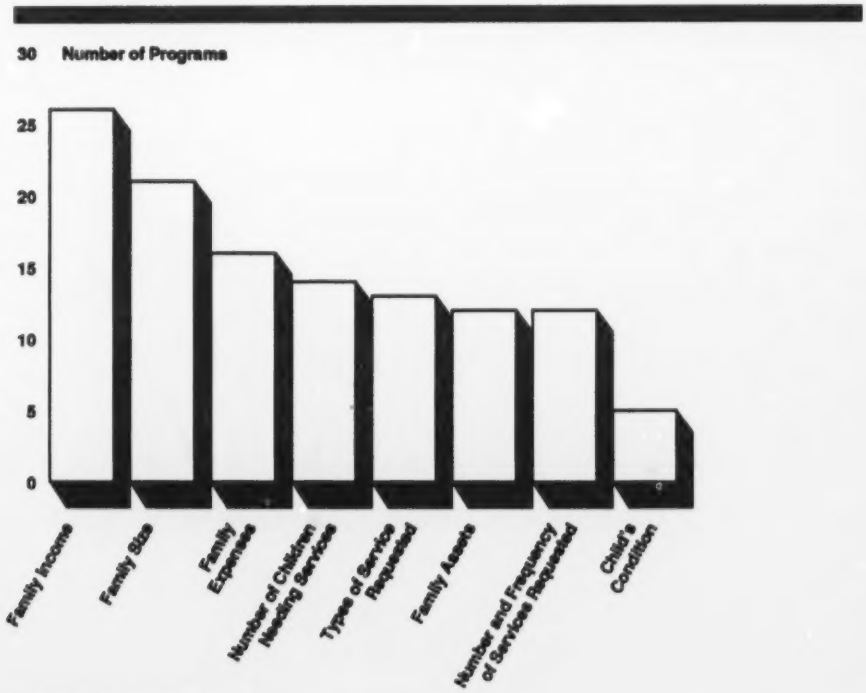
Figure III.3: Non-Respite Care Support Services Provided by 100 State-Funded Programs (FY 1988)



Fee Structure for Services

Seventy-nine of the 111 state-funded programs did not charge families and other caretakers for the respite care services provided. Of the 32 programs that charged a fee, 30 charged parents an amount based on a sliding scale. Figure III.4 shows the various factors used in determining the fee. In many cases, the fee was based on a combination of the factors.

Figure III.4: Factors Used by 30 State-Funded Programs in Determining Sliding Scale Fee for Respite Care Services (FY 1988)



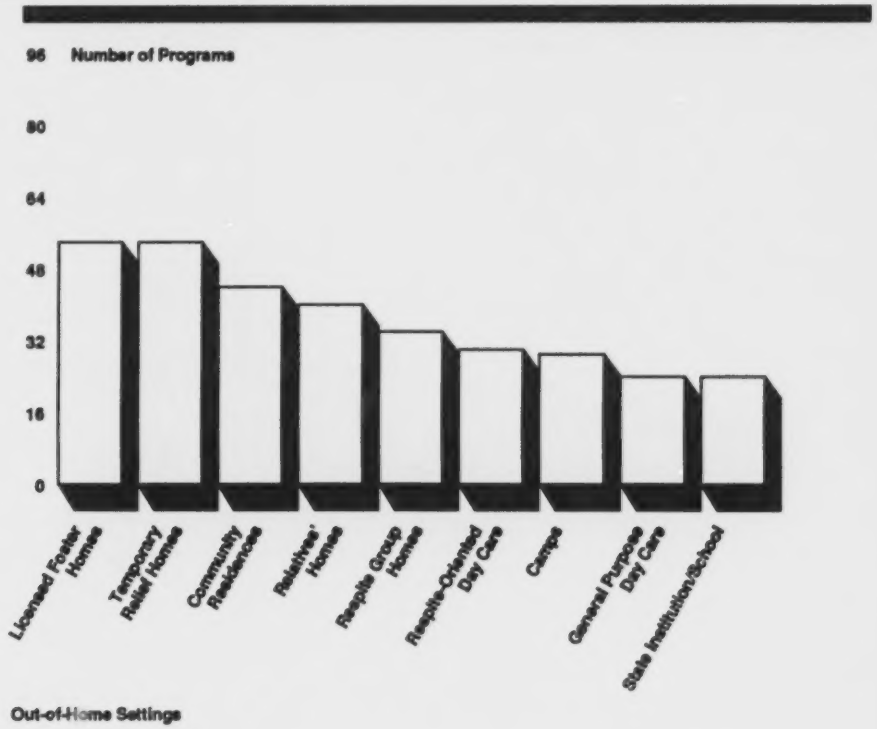
The state-funded respite care programs used one or a combination of methods to pay respite care providers for their services. Twenty-three programs gave families and other caretakers direct cash subsidies for respite care services, which allowed them to purchase the services and other items specifically needed for their child. Seventy-seven programs made direct payments to respite care providers, and 48 programs paid fiscal agents, who in turn paid the respite care providers.

Service Delivery Settings

Seventy of the 111 state-funded programs offered respite care services throughout the state, while 41 programs offered services only in specific geographic locations. Fifteen programs provided services only within the parents' or other caretaker's home; 24 programs provided services only in settings located outside the child's home; and 72 provided such services in both settings. As illustrated in figure III.5, the out-of-home settings included state institutions and camps that provided respite care for the family and camping experiences for the child. In addition, foster

care homes provided temporary respite care for children along with typical long-term foster care.

Figure III.5: Out-Of-Home Settings Used by 96 State-Funded Programs to Deliver Respite Care Services (FY 1988)



Sources of Respite Care Information

Most common among ten principal methods or sources through which state-funded programs informed the public about their respite care services were parent organizations, state-level departments, and handicapped advocacy programs (see table III.1).

Table III.1: Principal Sources of Information About Respite Care Services (FY 1988)

Information source	Number of programs
Parent organizations	76
State-level departments	74
Handicapped advocacy programs	73
School district special education programs	66
Local public health departments	61
Crippled childrens' programs	54
Private physicians' offices	53
Neonatal hospital units	52
Radio, television, newsprint, or other media	50
Parent or parent-teacher organizations	46

Provider Requirements and State Monitoring

Of the 111 programs, 91 had eligibility or licensing requirements for respite care providers. These included age, education, training, and licensing or certification by a profession or specialty, such as that required for a nurse or social worker. To ensure quality services, 91 programs monitored respite care providers by (1) requiring providers to maintain records of services provided, (2) following up with service recipients, and (3) making visits to sites where services were provided.

Number of State-Funded Respite Care Programs Having Certain Provider Eligibility or Licensing Requirements

Location of program	No. of programs having requirement			
	License or certification	Age	Education	Training
Alabama	1	0	0	1
Arkansas	1	2	1	1
California	2	1	3	3
Colorado	2	1	1	3
Connecticut	6	6	5	7
Florida	1	0	1	1
Iowa	1	0	1	1
Illinois	4	6	6	4
Indiana	1	2	1	2
Kentucky	1	2	1	2
Louisiana	3	3	2	2
Massachusetts	4	4	3	3
Michigan	3	4	0	3
Minnesota	3	1	0	2
Missouri	2	2	1	3
North Carolina	3	4	4	4
New Jersey	3	3	2	3
New York	2	0	3	3
Ohio	4	4	3	5
Oklahoma	3	4	3	4
Pennsylvania	1	1	1	1
Tennessee	1	3	1	3
Texas	2	1	1	1
Virginia	0	0	0	1
Washington	2	3	1	2
Totals	**56**	**57**	**45**	**65**

Note: Of the 111 state-funded respite care programs surveyed, 91 had provider eligibility or licensing requirements; 20 reported no such requirements.

Results of Questionnaire Administered to Officials of State-Funded Respite Care Programs

United States General Accounting Office

GAO

Survey of States

Programs That Provide Temporary Relief Services

U.S. General Accounting Office

Survey of State Programs that
Provide Temporary Relief Services

The U.S. General Accounting Office (GAO) is studying state programs that either primarily or in part serve children age 21 and younger, and as part of their services, offer temporary relief to their parents or caretakers. Generally, this temporary relief or "respite" is provided because the family members or caretakers are under significant stress or the children are at risk of abuse, neglect, or out-of-home placement.

The program shown on the label above was identified as one program in your state that funds or provides temporary relief to parents and caretakers of children. Please complete this questionnaire only for the program shown on the label. Please return your completed questionnaire in the enclosed pre-addressed business reply envelope within the next two weeks. If you have any questions about this questionnaire or our study, please call Ted Boyden on (313) 226-4031, Lisa Gardner on (313) 226-4038 or Annette Graziani on (313) 226-4034. They will be glad to help you. Thank you for your assistance.

Note: The label at the top of the page should contain the mailing address for this program. If any information on the label is incorrect, please make changes to the right of the label.

I. Background Information

1. Please provide the name, title, and telephone number of the individual we should contact if additional information is required.

   Name: _____

   Title: _____

   Telephone Number: (____) _____

2. During your fiscal year (FY) 1988, did your program fund or provide temporary relief services **only** or was temporary relief funded or provided in addition to other services? (CHECK ONE.)

   During FY 1988, the program...

   1. [10] funded/provided temporary relief **only** (GO TO QUESTION 4.)
   2. [100] funded/provided temporary relief **in addition** to other services (GO TO QUESTION 3.)
   3. [1] Missing

3. Listed below are additional services that programs might fund or provide. Please indicate whether or not your program generally funded or provided each of these services during your FY 1988. (CHECK "YES" OR "NO" FOR EACH.)

Service	Yes (1)	No (2)	Missing
1. Child or day care (e.g., ongoing child care)	39	61	11
2. Homemaker	47	54	10

3. (Continued.)

Service	Yes (1)	No (2)	Missing
3. Independent living skills	55	46	10
4. Home health care or nursing services	51	49	10
5. Medical services (i.e., services provided by a physician)	45	56	10
6. Occupational or physical therapy	52	49	10
7. Counseling (e.g., family, individual, etc.)	71	30	10
8. Other (PLEASE SPECIFY.)			

Note: Now think about your program's temporary relief services.

4. In what year did your program first begin to fund or provide temporary relief services?

   19 |__|__|

Before 1980	23
1980 - 1984	38
1985 - 1989	47
	108
	3 Missing
	111

5. During your fiscal year (FY) 1988, did your program fund or provide temporary relief services throughout your entire state or only in specific geographic locations? (CHECK ONE.)

   Services were funded/provided...

   1. [70] throughout the state

   2. [41] only in specific geographic locations

6. During your FY 1988, did your program ever conduct outreach (e.g., ads in papers, posters, etc.) to identify parents eligible for temporary relief services? **Note:** If your program conducted outreach for your services, in general, including temporary relief services, check the "Yes" box. (CHECK ONE.)

   1. [47] Yes

   2. [62] No

   3. [1] Don't Know

   4. [1] Missing

7. As of your FY 1988, had any state legislation specifically mandated your program to fund or provide temporary relief services? (CHECK ONE.)

   1. [19] Yes

   2. [92] No

II. Types of temporary relief services and service delivery settings

8. We would like to know where parents and caretakers of children could receive temporary relief services that were funded or provided by your program during your FY 1988. During that year, were your program's temporary relief services delivered 1) only within the parents and caretakers homes, 2) only outside the parents and caretakers homes or 3) in both settings? (CHECK ONE.)

Services were delivered...

1. [15] only within parents/caretakers homes (GO TO QUESTION 10 ON PAGE 6.)
2. [24] only outside parents/caretakers homes
3. [72] in both settings

---> (GO TO QUESTION 9.)

9. Please consider the settings **outside** of parents and caretakers homes where your program's temporary relief services were delivered during your FY 1988. During that year, were your program's temporary relief services 1) generally, 2) sometimes or 3) never delivered in each setting listed below. (CHECK ONE FOR EACH.)

Setting	Generally delivered in setting (1)	Sometimes delivered in setting (2)	Never delivered in setting (3)	Missing
1. Licensed foster homes	22	32	30	12
2. Temporary relief service providers' homes (other than foster homes)	15	39	34	5
3. Parent cooperative ("coop") members' homes	1	10	71	14
4. Family day care homes	1	17	64	14
5. Relatives' homes	5	35	41	15
6. Respite group homes	7	27	51	11
7. Crisis nurseries (exclude those located in a hospital)	4	6	71	15

Question 9 is continued on page 5.

9. (Continued.)

Setting	Generally delivered in setting (1)	Sometimes delivered in setting (2)	Never delivered in setting (3)	Missing
8. Respite-oriented day care centers	7	23	52	14
9. General purpose day care centers	8	16	58	14
10. Therapeutic preschools	3	17	61	15
11. Community residences (e.g., a residence for special needs persons which reserves beds for overnight or emergency respite)	4	40	40	12
12. Nursing homes	2	11	70	13
13. Pediatric hospitals (i.e., a hospital that usually provides acute or long-term care, but also provides overnight or emergency respite)	1	10	73	12
14. State institutions/schools	2	22	61	11
15. Camps	5	24	56	11
16. Churches/other religious buildings	0	14	69	13
17. Public schools	1	9	72	14
18. Other (PLEASE SPECIFY.)				

5

10. Listed below are types of temporary relief services your program may have funded or provided during your FY 1988. Please indicate whether each service was one your program 1) generally, 2) sometimes, or 3) never provided to parents and caretakers during your FY 1988. (CHECK ONE FOR EACH.)

Service	Generally provided service (1)	Sometimes provided service (2)	Never provided service (3)	Missing
1. Sitter services (i.e., temporary child care)	32	40	29	10
2. Companionship (e.g., mentors, "big brothers," etc.)	9	28	64	10
3. Personal care	40	31	31	9
4. Camping experiences	7	40	54	10
5. Social or recreational programs	17	38	49	7
6. Short-term residential care	24	35	42	10
7. Other (PLEASE SPECIFY.)				
8. Other (PLEASE SPECIFY.)				
9. Other (PLEASE SPECIFY.)				
10. Other (PLEASE SPECIFY.)				

11. During your FY 1988, did your program offer parents and caretakers transportation services between their homes and the settings where temporary relief services were provided? (CHECK ONE.)

1. [49] Yes
2. [61] No
3. [1] Missing

6

III. Eligibility for temporary relief services

Additional Instructions

We would like to know what eligibility criteria parents and caretakers of children must meet to receive temporary relief services through your program. We recognize that your program could:

1) only have general criteria to receive services, that would include temporary relief,
2) only have criteria specific to receiving temporary relief, or
3) both have general criteria and criteria specific to receiving temporary relief.

When answering questions 12 to 15 that follow, please consider **ALL** of your program's eligibility criteria, whether they were general or specific to temporary relief services.

12. During your FY 1988, did parents and caretakers of children have to be formally referred to your program to receive temporary relief services or could they directly request services? (CHECK ONE.)

    To receive services, parents/caretakers...

    1. [29] **had** to be formally **referred** to the program
    2. [80] could either be **referred** or **request** services from the program
    3. [2] Missing

13. During your FY 1988, for what age children did your program accept parents and caretakers of children for temporary relief services?

    From **birth** to _____

    OR

    From age _____ to _____

14. During your FY 1988, did your program have an income ceiling above which a parent or caretaker of children would be ineligible for temporary relief services? (CHECK ONE.)

    1. [16] Yes
    2. [94] No
    3. [1] Missing

7

15. We would like to know what condition or conditions children were **required** to have for their parents to be eligible for temporary relief services during your FY 1988. To be eligible for those services, did a child **have** to have any of the conditions listed below? (CHECK "YES" OR "NO" FOR EACH.)

Did the child have to be...	Yes (1)	No (2)	Missing
1. developmentally disabled (Please use Public Law 95-602 definition. Include autistic children)?	45	65	1
2. behaviorally or emotionally disturbed?	30	81	
3. mentally retarded?	38	73	
4. medically handicapped (e.g., requires the services of a licensed nurse or home health provider as an alternative to out-of-home placement)?	26	85	
5. physically handicapped (e.g., has limited strength, vitality, or alertness due to an acute or chronic health problem)?	25	85	1
6. chronically ill?	17	94	
7. terminally ill?	14	97	
8. foster children?	16	94	1
9. teen parents?	2	105	4
10. protected by Child Protective Services?	15	95	1
11. at risk of abuse or neglect (not protected by Child Protective Services)?	21	89	1
12. other (PLEASE SPECIFY.)?			

8

16. Listed below are sources through which programs might tell parents or caretakers about temporary relief services. During your FY 1988, did your program 1) generally, 2) sometimes, or 3) never use each source listed below to tell parents about your temporary relief services? (CHECK ONE FOR EACH.)

Source	Generally used source (1)	Sometimes used source (2)	Never used source (3)	Missing, Don't Know
1. Neo-natal hospital units	13	39	43	0/16
2. Nursing Associations	9	31	52	0/19
3. School district special education programs	19	47	34	0/11
4. Local public health departments	18	43	38	0/12
5. Private physicians'offices	7	46	43	0/15
6. Parent organizations	32	44	27	5/3
7. Handicapped advocacy programs	28	45	32	4/2
8. Crippled childrens' programs	24	30	41	9/7
9. Radio, television, newsprint, other media	18	32	50	6/5
10. Other state level departments	30	44	28	6/3
11. Parent or parent teacher organizations (e.g, PTAs, etc.)	14	32	50	10/5
12. Clergy	4	35	56	9/7
13. Civic associations	7	30	58	9/7
14. Informal neighborhood groups or associations	8	35	53	9/6
15. Other (PLEASE SPECIFY.)				

IV. Client costs for services

Additional Instructions

We would like to know whether your program charges parents and caretakers for temporary relief services and what factors are considered when determining what parents will pay for these services. We recognize that your program could:

1) charge for services in general, including temporary relief,
2) only charge for temporary relief services,
3) charge both for services in general and specifically for temporary relief, or
4) not charge parents for any services.

When answering questions 17 to 19 that follow, please consider **ALL** fees parents and caretakers paid to receive services through your program during your FY 1988, whether they were fees for services, in general, or specifically for temporary relief.

17. During your FY 1988, did your program charge any parents for temporary relief services? (CHECK ONE.)

1. [32] Yes (GO TO QUESTION 18.)

3. [79] No (GO TO QUESTION 20 ON PAGE 12.)

18. Please indicate which statement below best describes how your program charged parents and caretakers for temporary relief services during your FY 1988. (PLEASE REVIEW EACH STATEMENT, THEN CHECK ONE.)

1. [2] **All** parents were charged the **same** amount for services (e.g., a flat fee) (GO TO QUESTION 20 ON PAGE 12.)

2. [0] **Some** parents were **not** charged for services, all **other** parents were charged the **same** amount (GO TO QUESTION 19.)

3. [30] **Some** parents were **not** charged for services, **other** parents were charged **different** amounts based on a sliding scale (GO TO QUESTION 19.)

19. We are interested in how you decided how much or whether to charge parents and caretakers for temporary relief services. During your FY 1988, did you consider each factor below when making that decision? (CHECK "YES" OR "NO" FOR EACH FACTOR.)

Factor	Yes (1)	No (2)	Missing
1. Family income	26	2	2
2. Family assets	12	15	3
3. Family expenses	16	11	3
4. Size of family	21	5	4
5. Type of service requested	13	12	5
6. Number or frequency of services requested	12	13	5
7. Condition of child for which services were requested	5	21	4
8. Number of children for which services were requested	14	13	3
9. Other (PLEASE SPECIFY.)			

11

V. Eligibility requirements for temporary relief service providers and monitoring

20. During your FY 1988, did your program have any eligibility or licensing requirements for the people who actually provided temporary relief services (e.g., nurses, home health aides, etc.)? (CHECK ONE.)

1. [91] Yes (GO TO QUESTION 21.)

2. [20] No (GO TO QUESTION 22 ON PAGE 13.)

21. Listed below are types of eligibility or licensing requirements. During your FY 1988, did any of the people who provided your program's temporary relief services have to meet any of the requirements below. (CHECK YES OR NO FOR EACH.)

Did any temporary relief providers have to...	Yes (1)	No (2)	Missing
1. be licensed/certified in a specialty (e.g., a licensed practical nurse, registered nurse, foster parent, etc.)	56	35	
2. be of a certain age (e.g., must be 21 years of age)	57	33	1
3. have a specific amount or kind of education	45	44	2
4. have a specific amount or kind of training	65	25	1
5. Other (PLEASE SPECIFY.)			
6. Other (PLEASE SPECIFY.)			
7. Other (PLEASE SPECIFY.)			

22. During your FY 1988, did your program ever monitor temporary relief service providers (e.g., make site visits, review reports, etc.) **Note:** If your program monitored temporary relief providers as part of a general monitoring effort, check the "Yes" box. (CHECK ONE.)

1. [91] Yes (GO TO QUESTION 23.)
2. [18] No (GO TO QUESTION 24 ON PAGE 14.)
3. [2] Missing

23. Listed below are methods that could be used to monitor temporary relief providers. Please indicate whether or not your program used each method during your FY 1988. (CHECK ONE FOR EACH.)

Method	Yes (1)	No (2)	Missing
1. Required providers to submit reports	68	22	3
2. Made site visits where services were provided	71	19	3
3. Made site visits to service providers' administrative offices	55	34	4
4. Followed-up with parents who received services	76	15	2
5. Required providers to maintain records of services provided	80	11	2
6. Other (PLEASE SPECIFY.)			

VI. Funding sources

24. Please record your program's total expenditures for temporary relief service for your FY 1988. Also, please record about how much of the expended funds were from each of the sources listed below (e.g. federal, state, etc.)? (Please consider all direct and indirect expenses, e.g., personnel, overhead, etc. and record actual numbers or reasonable estimates; if necessary, record a percentage. If information is unavailable, check the Don't know "D/K" box.)

	Dollars Expended	Percentage	D/K
1. Total FY 1988 expenditures for your **temporary relief services**	$	******* *******	
a. Federal government funds	$ 6,710,000	%	
b. State government funds	$ 76,320,000	%	
c. Local government funds	$ 250,000	%	
d. Fees from parents	$ 190,000	%	
e. Other (PLEASE SPECIFY.)	$ 400,000	%	
Note: The total of 1a - 1e should equal "1 - Total FY 1988 expenditures for your **temporary relief services**"	$83,870,000	100%	

25. During your FY 1988, was there a "cap" on the total amount of funds that your program had available for temporary relief services? (CHECK ONE.)

1. [71] Yes
2. [37] No
3. [3] Missing

26. We would like to know how your program paid providers for temporary relief services during your FY 1988. Please indicate if your program 1) generally, 2) sometimes or 3) never used each method listed below to pay providers for temporary relief services during your FY 1988. (CHECK ONE FOR EACH.)

Method	Generally used method (1)	Sometimes used method (2)	Never used method (3)	Missing
1. Gave parents and caretakers cash subsidies to purchase temporary relief services.	10	13	81	7
2. Directly paid providers of temporary relief services.	62	15	29	5
3. Provided money to a fiscal agent that paid providers.	37	11	57	6
4. Other (PLEASE SPECIFY.)				

15

VII. Characteristics of people served

27. We would like to know what kinds of information states maintain on people that request or receive temporary relief services. Does your program have any data on the **number** of people who requested or received temporary relief services during your FY 1988? (CHECK ONE.)

1. [76] Yes (GO TO QUESTION 28.)

2. [35] No (GO TO QUESTION 31 ON PAGE 17.)

28. Please record the information requested below for your FY 1988. **If none, enter a "0." If you cannot provide a reasonable estimate, check the "Don't know" box.**

In total, how many...	Number	Don't Know
a. Families **requested** temporary relief services from your program?	10,163	
b. Children were in these families?	5,249	
c. Families **received** temporary relief services?	45,712	
d. Children were in these families?	29,309	

29. Does your program have any information on the **characteristics** (e.g., race, income, etc.) of the families who requested OR received temporary relief services (e.g., the families you recorded for question 28a or 28c above)?

1. [46] Yes

2. [29] No

3. [1] Missing

30. Does your program have any information on the characteristics of the **children** in families who **received** services during FY 1988 (the children entered in item 28d above)?

1. [49] Yes

2. [29] No

3. [1] Missing

31. During your FY 1988, did your program ever refer any families to other programs for temporary relief services? (CHECK ONE.)

1. [77] Yes (GO TO QUESTION 32.)

2. [28] No (GO TO QUESTION 33.)

3. [6] Missing

32. Listed below are reasons why programs might refer parents or caretakers to other programs for temporary relief services. Please consider the parents and caretakers your program referred to other programs for temporary relief services during your FY 1988. About what proportion of these parents and caretakers did your program refer for each reason below? (If necessary, please use the Don't know "D/K" box.) (CHECK ONE FOR EACH.)

Reason for referral	All or almost all (1)	Most (2)	About half (3)	Some (4)	Few or none (5)	D/K (6)	Missing
1. Parents/caretakers were ineligible for services	7	4	1	20	27		24
2. Parents/caretakers had special service needs for temporary relief (e.g., child had a particularly disabling or unique condition)	4	4	1	26	25		23
3. Parents/caretakers requested more services than were available through program	6	5	2	31	16		23
4. Number of parents/caretakers requesting services was greater than the supply of services	10	10	3	16	25		19
5. Other (PLEASE SPECIFY.)							

33. During your FY 1988, did your program ever maintain a waiting list of families that requested temporary relief services? (CHECK ONE.)

1. [40] Yes (GO TO QUESTION 34.)

2. [69] No (GO TO QUESTION 37 ON PAGE 19.)

3. [2] Missing

34. During your FY 1988, in total, about how many families were ever on your waiting list for temporary relief services? (If you cannot provide an exact number or a reasonable estimate, please check the Don't know box.)

3,671 Families on a waiting list

OR [ ] Don't know

35. Please consider the families you recorded in question 34 above. On average, how many weeks did these parents remain on your waiting list before receiving temporary relief services? (If you cannot provide an exact number or a reasonable estimate, please check the Don't know box.)

_____ Average number of weeks

OR [ ] Don't know

36. As of your FY 1988, did any state legislation limit the number of families that could receive your program's temporary relief services? (CHECK ONE.)

1. [5] Yes

2. [36] No

3. [1] Missing

VIII. Other

37. Have any studies been conducted on the effectiveness of your temporary relief services in meeting your program's objectives (e.g., reducing stress or abuse, keeping families together, etc.)? (CHECK ONE.)

1. [24] Yes (PLEASE SEND US A COPY OF ANY SUCH STUDIES.)
2. [85] No
3. [2] Missing

38. Does your program have a list of your temporary relief service providers? (CHECK ONE.)

1. [39] Yes (PLEASE SEND US THIS LIST TO HELP US IDENTIFY LOCAL LEVEL CONTACTS FOR A NATIONAL DIRECTORY OF PROVIDERS.)
2. [70] No
3. [2] Missing

39. Please use the space below for any additional comments you might have on temporary relief services, this questionnaire or our study.

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Number of Local Chapters of National Organizations With Respite Care Programs, by State(FY 1989)

State	National Easter Seal Society	Camp Fire[a]	United Cerebral Palsy Association, Inc.	National Down Syndrome Society	The National Council on Aging, Inc.[b]	Visiting Nurse Association of America	Total
Alabama	1	1	4	0	0	1	**7**
Alaska	0	0	0	0	0	0	**0**
Arizona	0	0	0	0	0	0	**0**
Arkansas	1	0	1	0	0	1	**3**
California	1	9	5	1	2	7	**25**
Colorado	0	3	0	0	0	4	**7**
Connecticut	1	1	0	0	1	0	**3**
Delaware	1	0	1	0	0	1	**3**
District of Columbia	1	0	0	0	1	1	**3**
Florida	0	5	3	2	1	9	**20**
Georgia	0	2	1	0	0	1	**4**
Hawaii	3	0	1	0	0	0	**4**
Idaho	0	1	0	0	0	0	**1**
Illinois	2	5	2	0	0	6	**15**
Indiana	0	2	0	0	0	5	**7**
Iowa	2	3	0	0	0	0	**5**
Kansas	0	1	0	0	0	0	**1**
Kentucky	1	0	0	0	0	1	**2**
Louisiana	1	3	1	0	0	0	**5**
Maine	0	2	1	0	0	1	**4**
Maryland	0	2	2	0	0	0	**4**
Massachusetts	0	1	0	0	0	3	**4**
Michigan	1	4	1	0	0	7	**13**
Minnesota	0	3	0	0	0	0	**3**
Mississippi	0	0	0	0	0	0	**0**
Missouri	0	1	1	0	0	5	**7**
Montana	0	0	0	0	0	0	**0**
Nebraska	0	1	0	0	1	1	**3**
Nevada	1	0	1	0	0	0	**2**
New Hampshire	1	1	0	0	0	1	**3**
New Jersey	0	1	3	0	0	2	**6**
New Mexico	0	1	0	0	0	0	**1**
New York	1	3	8	2	0	4	**18**
North Carolina	2	0	0	0	0	0	**2**
North Dakota	1	1	0	0	0	0	**2**
Ohio	4	1	2	0	1	2	**10**
Oklahoma	0	1	0	0	0	1	**2**

(continued)

State	National Easter Seal Society	Camp Fire[a]	United Cerebral Palsy Association, Inc.	National Down Syndrome Society	The National Council on Aging, Inc.[b]	Visiting Nurse Association of America	Total
Oregon	2	4	0	0	0	1	**7**
Pennsylvania	1	3	4	0	0	8	**16**
Rhode Island	0	1	0	0	0	2	**3**
South Carolina	0	0	0	0	0	0	**0**
South Dakota	1	0	0	0	0	0	**1**
Tennessee	1	1	1	0	0	2	**5**
Texas	1	9	0	0	1	5	**16**
Utah	1	0	1	0	1	1	**4**
Vermont	0	1	0	0	0	0	**1**
Virginia	3	1	0	0	0	0	**4**
Washington	0	10	0	0	0	1	**11**
West Virginia	0	0	0	0	0	0	**0**
Wisconsin	1	0	6	0	1	3	**11**
Wyoming	0	1	0	0	0	0	**1**
Puerto Rico	0	0	0	0	0	0	**0**
Totals	**37**	**90**	**50**	**5**	**10**	**87**	**279**

[a]Special Sitters Program

[b]Family Friends Program

Federal Respite Care Grants Awarded, by State (1983-89)

State	Department of Health and Human Services Under P.L. 99-401		Other[c]	Department of Education	Action	Total
	Section 204[a]	Section 203[b]				
Alabama	0	1	0	0	0	**1**
Alaska	0	0	1	0	0	**1**
Arizona	1	0	0	0	0	**1**
Arkansas	1	1	0	0	0	**2**
California	2	1	1	1	0	**5**
Colorado	1	1	1	0	0	**3**
Connecticut	1	1	0	0	0	**2**
Delaware	0	1	1	0	0	**2**
District of Columbia	0	0	1	1	0	**2**
Florida	1	2	0	0	0	**3**
Georgia	0	1	0	0	0	**1**
Hawaii	1	1	0	0	0	**2**
Idaho	2	0	0	0	0	**2**
Illinois	1	1	0	0	0	**2**
Indiana	1	0	0	0	0	**1**
Iowa	1	0	0	0	0	**1**
Kansas	0	1	0	0	0	**1**
Kentucky	0	0	0	0	0	**0**
Louisiana	1	0	0	0	0	**1**
Maine	0	0	1	0	0	**1**
Maryland	1	0	0	0	0	**1**
Massachusetts	0	2	2	1	0	**5**
Michigan	1	1	0	0	0	**2**
Minnesota	0	0	0	0	0	**0**
Mississippi	0	1	0	0	0	**1**
Missouri	1	1	0	0	0	**2**
Montana	0	0	0	0	0	**0**
Nebraska	0	1	1	0	0	**2**
Nevada	1	0	0	0	0	**1**
New Hampshire	0	1	0	0	0	**1**
New Jersey	1	1	0	0	0	**2**
New Mexico	1	0	1	0	0	**2**
New York	0	1	3	0	1	**5**
North Carolina	2	2	0	0	0	**4**
North Dakota	1	1	0	0	0	**2**
Ohio	1	0	0	0	0	**1**
Oklahoma	1	1	0	0	0	**2**
Oregon	1	0	0	0	0	**1**

(continued)

State	Department of Health and Human Services Under P.L. 99-401		Other[c]	Department of Education	Action	Total
	Section 204[a]	Section 203[b]				
Pennsylvania	1	1	0	0	0	**2**
Rhode Island	1	1	0	0	0	**2**
South Carolina	1	0	0	0	0	**1**
South Dakota	0	0	0	0	0	**0**
Tennessee	0	2	0	0	0	**2**
Texas	1	1	0	0	0	**2**
Utah	1	0	0	0	0	**1**
Vermont	0	1	0	0	0	**1**
Virginia	0	1	0	0	0	**1**
Washington	1	0	1	0	0	**2**
West Virginia	0	0	0	0	0	**0**
Wisconsin	1	0	1	0	0	**2**
Wyoming	0	0	0	0	0	**0**
Puerto Rico	2	0	0	0	0	**2**
Totals	**35**	**32**	**15**	**3**	**1**	**86**

[a]Crisis nursery grants.

[b]Grants for temporary child care for handicapped and chronically ill children.

[c]Grants awarded by HHS's Administration on Developmental Disabilities and Administration for Children, Youth, and Families, both under the Office of Human Development Services.

Comments From the Department of Health and Human Services

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

JUL 9 1990

Mr. Franklin Frazier
Director, Income Security Issues
United States General
Accounting Office
Washington, D.C. 20548

Dear Mr. Frazier:

Enclosed are the Department's comments on your draft report, "Respite Care: An Overview of Federal, Selected State, and Private Programs." The comments represent the tentative position of the Department and are subject to reevaluation when the final version of this report is received.

The Department appreciates the opportunity to comment on this draft report before its publication.

Sincerely yours,

Bryan Mitchell
For Richard P. Kusserow
Inspector General

Enclosure

COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES ON THE U.S. GENERAL ACCOUNTING OFFICE'S REPORT, "RESPITE CARE: AN OVERVIEW OF FEDERAL, SELECTED STATE, AND PRIVATE PROGRAMS" (GAO/HRD-90-125)

General Comments

Generally, we agree with the information and suggestions in the report for improving respite care services. Although data on the use and availability of respite care services are limited, it is clear that there is a need and a demand for these services.

Under Public Law 99-401, the Temporary Child Care and Crisis Nurseries Act, and Public Law 101-127, the Children with Disabilities Temporary Care Reauthorization Act of 1989, the Office of Human Development Services (OHDS) has funded 67 demonstration grants in fiscal years (FY) 1988 and 1989 and expects to make additional grant awards in FY 1990. The purpose of these projects is to provide respite care to disabled children; children with chronic or terminal illnesses; and abused and neglected children, including those at risk of abuse and neglect. Public Law 101-127 also requires States to begin data collection as a step toward evaluating the effects of respite care programs. In addition, the 1988 and 1989 projects which OHDS funded are voluntarily participating in an independent assessment which should be completed by the end of 1990. At that time, OHDS will be able to provide some basic program data, with the expectation of a more complete evaluative capability in fiscal year 1992 when the law's data collection requirements have taken full effect.

The draft report acknowledges that information on respite care is limited regarding the supply of services available, the number of families served, the extent of unmet demand for services, and the efficacy of the services rendered. The draft report's suggestions for improving services should be contingent on the availability of additional data before formulating public policies.

Major Contributors to This Report

Human Resources Division, Washington, D.C.	David P. Bixler, Assistant Director, (202) 275-8610 Daniel M. Brier, Assistant Director Patricia A. Cole, Assignment Manager Joanne R. Frankel, Technical Advisor
Detroit Regional Office	William F. Laurie, Evaluator-in-Charge Theodore F. Boyden, Site Senior Lisa P. Gardner, Staff Evaluator Annette S. Graziani, Staff Evaluator

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